

‘Client satisfaction’—guidelines for assessing the quality of leprosy services from the clients’ perspective

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Summary In order to ensure that leprosy patients are detected and treated adequately, it is essential that they are satisfied with the services provided. Their satisfaction can be analysed by assessing the quality of the services from a client perspective. This will give crucial information for the identification of strengths and weaknesses of leprosy services, e.g. in areas such as health seeking behaviour and regularity of treatment. It necessitates, however, that special attention is given to clients’ opinions and ideas, both of which are rarely included in reviews and evaluations of leprosy programmes. Hence, an initiative was taken to formulate guidelines for the conducting of a study on client satisfaction. These guidelines were pre-tested in two countries, Nepal and Brazil. The development and contents of these guidelines are highlighted and discussed in this paper.

Introduction

Every year, over half a million new leprosy patients are detected.¹ Since there is no evidence that the transmission in high endemic countries has been substantially interrupted, it is expected that in the coming years considerable numbers of leprosy patients will continue to report to health facilities.² Therefore, it is crucial that leprosy services are sustained and that they remain of good quality. This requires that regular feedback from the ‘clients’ of these services, i.e. the patients and communities, is obtained and analysed. Information on the experiences and opinions of the clients is, for instance, essential in understanding their motivation to consult health facilities and to take their treatment regularly.³ Furthermore, it is important to determine whether the services continue to satisfy the ideas and perceptions of the patients. Such information can be used to enhance early detection and adequate adherence to treatment.

Evaluations of leprosy control programmes tend to focus primarily on the analysis of the

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performance and impact of the programme, often expressed in epidemiological and output indicators.^{4,5} An adequate approach to assess the clients' perception of the programme, and what the interventions mean for them, is usually lacking.⁶ At the same time, large-scale surveys on these aspects are often unfeasible or are too expensive.

As an initiative of the Netherlands Leprosy Relief (NLR), a workgroup was formed to develop guidelines for a study on client satisfaction in leprosy control programmes. Such a study should give a reasonable impression of the clients' views on a range of quality aspects of leprosy services. The study, however, should be small-scale and feasible within a short time-span (1 month) and should lend itself to conducting by local researchers. Furthermore, the guidelines needed to be developed in a way that they can be used in different countries and settings.⁶

In this article, we first describe the development of the guidelines. Then we will present the major outline and contents of the guidelines. Finally, we will discuss some of the limitations and strengths of the study, and will elaborate on some practical aspects. This will be illustrated by summarizing the results of two pilot studies conducted in Brazil and Nepal.

Methodology for the development of guidelines

In order to define the concept 'client satisfaction', which is sometimes referred to as 'patient' or 'customer' satisfaction, a literature review was conducted. A core dilemma highlighted in most studies on client satisfaction is that it is not clear what patients actually mean when they say they are 'satisfied' with a particular aspect of the health services.^{3,7-11} In many studies, it is assumed that patients actively evaluate and criticize the services. As a result, reports of overall satisfaction tend to be flatteringly high (often over 90%), whereas these rates do not necessarily mean high levels of quality of care.^{3,7} Sixma and van Campen,¹²⁻¹⁴ however, suggest a more practical approach by using the concept of 'quality of care from the patients' perspective'. Their approach concentrates on the basic components of satisfaction: expectations or 'needs', and the experiences of patients. The conceptualization of 'client satisfaction' for the development of the guidelines is based on this approach. Rather than asking respondents whether they are satisfied or dissatisfied, it is necessary to pose open-ended questions as to their actual experiences, and to obtain their opinions and perceptions regarding a range of aspects of leprosy services. When asked to suggest improvements, the respondents actually disclose patients' 'needs'.

With the aim of further operationalizing the concept, a range of aspects that relate to the quality of leprosy services was selected (see Box 1).

Information on patients' priorities can indicate where quality improvements might be most advantageous. Therefore, it was considered important to assess the priorities that patients have with regard to different aspects of the health services.^{10,13,14} Hence, a simple method had to be developed for this purpose.

Different data collection methods were utilized, in order to compare and validate the results. In addition to interviews, focus group discussions (FGDs) were included in the study methodology. Furthermore, not only patients, but also health staff and community members were targeted in the study. The reason for including community members is that they are also regarded as 'clients' of the services. Opinions of the community on the services can influence health seeking behaviour. Health staff members are interviewed in order to contrast their

Box 1. Aspects of quality of leprosy services explored in study

Health seeking behaviour (use of self- or traditional care, patient and doctors' delay)
 Health education to community (quality, method)
 Accessibility (costs, waiting time)
 Condition of facilities (building, cleanliness, toilets)
 Diagnostic procedures (privacy, dealing with gender difference)
 Information to patients (quality, method)
 Contact examination
 Health staff attitude, continuity and technical competence
 Treatment (availability of drugs, dealing with non-compliance)
 Prevention of disabilities (quality, advice/attitude of staff)
 Stigma and socio-economic consequences (advice on dealing with stigma)

views with those of the clients. This would also indicate whether they are aware of and amenable for the constraints identified by the clients.

When the basic concepts and methodology were operationalized into a more systematic and practical approach, draft guidelines for conducting the study were designed. The guidelines were pre-tested in two NLR-supported leprosy control projects (Eastern Region of Nepal and Minas Gerais in Brazil). The focus of these pre-tests was mainly to try out sampling procedures and data collection tools, which were adjusted where necessary. After the first two studies, which were conducted by an experienced anthropologist, a final pre-test was held in a third NLR-supported leprosy control project (Far Western Region, Nepal). This was conducted by a team of two local researchers, who conducted the study by using the draft guidelines. Although the anthropologist was present during the study period, she did not participate in conducting it and assisted only when this was necessary. In this way, problems or unclear elements in the guidelines could be identified. The guidelines were further developed and adjusted accordingly.

Outcome

The direct result of the exercise was the publication 'Client satisfaction—Guidelines for assessing the quality of leprosy services from the clients' perspective'.¹⁵ The guidelines explain on a step-by-step basis how a study on client satisfaction can be organised and conducted. They describe how the study is divided into three phases: 1) planning and preparation of the study, 2) field work and 3) analysis and report writing (see Table 1).

In phase 1 the preparations for the study should be made, mainly by the programme manager. The study period should be planned, a budget should be included in the plan of activities and, if necessary, approval for the study must be sought from the relevant authorities. A research team should also be selected, and concrete criteria for this step are provided in the guidelines. In addition, logistics and allowances need to be arranged, interview questions may need to be translated, and 'priority cards', i.e. cards with drawings of several quality aspects, should be prepared.

Phase 2 consists of the actual field study. It starts with a preparatory meeting in which the programme manager briefs the researchers and other stakeholders on the objectives and methodology of the study. A selection of health facilities to be visited is made according to

Table 1. Basic outline of study

Period	Action	Responsible person(s)
<i>Phase 1. Planning and preparation</i>		
Year before end evaluation	1.1 Plan the study period	Programme manager
	1.2 Prepare budget and include, when relevant, in the Plan of Activities	
	1.3 Request approval from the Ministry of Health, if necessary	
- 120 days	1.4 Select 2 researchers	Programme manager
- 60 days	1.5 Plan logistics	Programme manager
- 14 days	1.6 Translate questionnaires, if necessary	Programme manager
	1.7 Copy questionnaires and prepare 'priority cards'	
<i>Phase 2. Field work</i>		
Day '0'	2.1 Organize preparatory meeting	Programme manager
	2.2 Select districts and health facilities within programme area	Research team
	2.3 Inform health facilities of the visit dates	
	2.4 Discuss methodology and data analysis	
Days 1–6	2.5 Select respondents and conduct interviews	Research team
Days 7–8	2.6 Conduct focus group discussions	Research team
<i>Phase 3. Analysis and report writing</i>		
Days 9–19	3.1 Analyse data	Research team
	3.2 Write report	
Day 20	3.3 Submit report to programme manager	Research team
Day 26	3.4 Discuss results with programme staff	Research team
	3.5 Submit report to relevant stakeholders	Programme manager

the sampling procedures provided in the guidelines. The study aims to cover a representative sample of districts (or equivalent) in the programme area, in which approximately six health facilities offering leprosy services are selected. The sample of respondents consists of 20–25 leprosy patients, six community members and six health staff members.

The next steps concern data collection by means of interviews. Two FGDs are also included in the study, each involving five to eight leprosy patients. Interview and FGD skills are explained in annexes of the guidelines. The questionnaires and priority cards are attached as annexes as well.

The third and final phase involves data analysis and report writing. Since the analysis has to be conducted in a limited period by researchers who might not have much experience with qualitative data analysis, a simple method is applied, using a checklist. The data resulting from the interviews and FGDs are analysed according to the issues raised in the checklist. Although the processing of data via master sheets is suggested, direct analysis of the raw data by discussing or describing the checklist issues is also possible. Results are outlined in a report and recommendations are formulated. Finally, the guidelines indicate how the results of the study can be disseminated among the relevant stakeholders.

Discussion

The major challenge in developing guidelines for a study on client satisfaction was to find a balance between certain criteria for good scientific research and the feasibility of a study

Box 2. Experiences with pilot studies in Brazil and Nepal*Pilot study in Brazil*¹⁶

In Minas Gerais leprosy is one of the priority diseases and has been integrated into the general health services. Family Health Programme (PSF) teams have been formed to provide basic care to the population. Patients are now usually be diagnosed and treated by general health workers.

In the pilot study, 19 patients were interviewed and two focus group discussions were carried out. In addition, five health workers and six community members were interviewed. The study revealed that patients, delayed mostly months to years before they go to a public health facility. This is due to the poor knowledge about leprosy, many fear the diagnosis and do not realize that leprosy is curable disease. Most of the interviewed patients tried to get rid of the symptoms at home, for instance by using herbs and ointments on the lesions or by rubbing alcohol on numb hands and feet. Distance was not regarded as a problem, though for a few poor and unemployed patients the transportation costs were high.

More than one-third of the patients were initially not diagnosed by health workers as having leprosy. Interviews with the health staff confirmed that misdiagnosis is still common. They stressed the need for training, particularly of the new PSF-teams. Patients complained that the waiting times to consult a doctor are long, often more than an hour. Most patients felt that the treatment received was adequate. The attitude of the health professionals was good and similar to the attitude towards other patients. Privacy was usually respected during clinical examinations and the health facilities were regarded as clean and well equipped. Most patients did not mind whether a person of the opposite sex examines or treats them. Patients considered the information given about leprosy to be very important. Almost all of them were invited to bring their contacts.

More than half (12 of the 19) of the patients interviewed explained that their social life is strongly influenced by the disease and that they suffer from the stigma at work, in their families and within their communities. Some even had to stop working and many had lost friends and contacts. The diagnosis of leprosy (or Hansen's disease) mostly came as a severe shock to them. Most patients were aware of the main aspects of leprosy and its treatment. Though MDT drugs are always available, several patients faced shortages in prednisolone for reaction treatment. Some patients are irregular, and a limited number of patients default. The tracing system using letters, telephones and house-visits, worked well and was appreciated by all patients.

The ranking system revealed that patients considered the important aspects of the quality of services to be: adequate information, availability of drugs, the possibility of contact examination and the attitude of health workers. There was a strong concordance between the opinions of the patients, community members and health workers.

Important recommendations resulting from the pilot study were:

- Health education to the public has to be strengthened.
- Financial support to patients that cannot pay transportation costs.
- Training of the recently established Family Health Programme (PSF) teams.
- Prednisolone stocks should be sufficient at all facilities.

Pilot study in Nepal¹⁷

The pilot study in Nepal was conducted in the Far Western Development Region. It was based on interviews with 21 leprosy patients, five community members and 6 health staff members. In addition, two focus group discussions with patients were conducted.

Contrary to Brazil only few (five) patients took any action at home. Many visited a private or traditional doctor. There is usually a substantial time span between the onset of the first symptom and a visit to a health facility where MDT is available. Eight of the interviewed patients (42%) reported to a health centre only after more than a year. Nevertheless, patients come earlier to the health facility than some years ago. Contrary to Brazil, patients are rarely misdiagnosed.

For most patients, distance was not a limiting factor in the accessibility of the health facilities. Waiting times were relatively short. However, privacy during examinations was seen as very crucial by patients. In most health facilities this was adequate. In Nepal patients had a strong preference for a health worker of the same sex. Leprosy patients and their communities did not regard contact tracing and examination as a high priority. Health workers were often frustrated by the lack of success for this type of case-finding. Patients placed a priority on health staff being friendly and respectful to them. Most patients indicated that staff had a good attitude and adequate skills to treat them properly. Despite health education, patients were relatively ignorant about some important aspects of the disease such as the cause and infectiousness of leprosy.

The study indicated that defaulting, a core problem, was caused by temporary migration. Emphasis on the prevention of disabilities (POD) was regarded as very important. Most patients were satisfied with the way this was handled by the programme. Patients felt that, as a result of health education, the stigma against leprosy has been reduced over the past years. Only a few complained about the socio-economical consequences. This change was confirmed by the community members and the health staff.

When patients were asked to list their priorities, they mentioned POD, good trained health workers, adequate information and the availability of drugs as their top four (out of 12) items. In Nepal the following were among the recommendations:

- More emphasis should be given to contact examination.
- Private doctors should be involved in the leprosy control programme.
- Education to the patients about the disease itself.
- MDT should be provided for the patients who migrate for work.

FOLLOW-UP

The conclusions and recommendations were discussed with the programme coordinators and their staff. Though sometimes health staff had some reservations about a study in which patients were interviewed without their presence, they appreciated the study and its results. During the discussions consensus could be reached about the most important recommendations and the feasibility of implementation.

under field circumstances. Hence, on the one hand, certain conditions had to be fulfilled for data collection and data analysis, for instance related to the number of respondents as well as the methodology used. Not only should at least about 20 patients be interviewed through semi-structured questionnaires, but FGDs also have to be organized to enrich and strengthen the data collection process. In order to further validate the information through triangulation, community members and health workers have to be interviewed. On the other hand, the study had to be developed into a very practical tool that can be used to gain good insight into the quality of the leprosy control programme. The conclusions and recommendations should enable programme managers to develop new policies and concrete actions.

The three pre-tests carried out in the development of the guidelines, demonstrated that it is possible to conduct a study on client satisfaction. The studies presented new and useful information on the leprosy services based on the experiences of the patients. In Box 2 the results of the last two pilot studies are briefly summarized. They highlight that the use of qualitative data collection methods enables assessment of the patients' perspective concerning leprosy services as well as the simultaneous identification of new ideas.

The implementation of the studies can also have a direct positive impact on the programme itself, as was already experienced during the pre-tests. The interviews sometimes proved to be not only a way of gathering information, but also a means of action itself. Patients, given the opportunity to express their opinions, gain a sense of awareness that they have the ability or power to improve their situation. Moreover, some of the interviewed health workers indicated that new issues, which they had not previously thought about, were discussed during the interviews. Hence, a process of self-analysis and reflection was generated, which could lead to new insights into their own functioning.

A study such as that presented in this paper, has of course certain limitations, since a compromise has to be found between the extent of the study and its feasibility in terms of time, money and manpower. The study cannot replace more scientific research on client satisfaction, or deeper research into some detailed aspects such as health seeking behaviour and defaulting. Though about 20 patients are interviewed, the sample is still relatively small. Moreover, sampling may not be at random, and informal interviewing approaches are used. While the study has been developed in such a way that 'socially desirable' answers are limited, it will be difficult to avoid them completely. Therefore, it is important that these potential biases and factors are taken into account when analysing and using the results of the study. These issues should also be mentioned in the final study report.

Furthermore, an important assumption is that local researchers can conduct the study based on the guidelines, without any prior training on methodology and data analysis. The last pre-test indeed indicated that local researchers have the capacity to conduct the study. However, it remains important to be critical when selecting the researchers, particularly since the success of the study very much relies on the performance of the research team.

Future use of the guidelines can provide valuable inputs for evaluations of leprosy control programmes. However, the study can also be conducted as a separate activity, independent of programmes and evaluations. If implemented on a regular basis, such studies will contribute to a better understanding of the clients' perspective of the leprosy services, and will eventually help to further improve the leprosy services, to the satisfaction of both the providers as well as the clients.

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